Cycling for a Cure

On Sunday February 25th 48 cyclists spun for a cure for myasthenia gravis at CycleBar Leawood. The charity ride benefiting the MGA was the first ever ride at CycleBar Leawood to sell out all 48 bikes! In fact, 2 individuals were on a waiting list to ride. It was an hour of fun and $1475 was raised for the MGA. Riders enjoyed snacks and drinks after the ride. CycleBar, we will be back! Thank you to all who participated and donated! Special thanks to CycleBar for hosting the MGA.

The MGA wishes to express our heartfelt appreciation to the Yokota Foundation which recently gave $40,000 to the MGA. St. Louis member, Mark Macias, his girlfriend Greta and sister and brother-in-law John and Tina Warren recently presented the check to the MGA. With the support of the Yokota Foundation the MGA is able to continue reaching those in the heartland affected by MG. Thank you!
Antibodies directed towards acetylcholine receptors (AChR) in MG were identified in 1976. About 85% of patients with generalized MG and 50% of patients with ocular (affecting only the eyes) MG have the AChR antibodies. For the group of patients without the antibodies, the question arises whether this is related to the presence of low-affinity antibodies that are capable of disease induction but not detectable by the standard assay. Some researchers suggest another possibility: that antibodies may be directed towards other target antigens and produce similar symptoms. In 2000, muscle-specific kinase (MuSK) antibodies were detected in about 40% of the patients who do not have the AChR antibodies and recently anti-agrin antibodies, low-density lipoprotein related protein 4 (LRP4) antibodies and Cortactin antibodies have been identified in some of the patients who do not have the AChR or MuSK antibodies. The main value of anti-striational muscle antibodies has been in predicting thymoma. In addition to these antibodies, research is ongoing presently to identify antibodies to other targets. While elevated serum concentrations of the antibodies assure the diagnosis of MG, normal concentrations of the antibodies do not exclude the diagnosis of MG. Seronegative MG (SNMG) was a term previously used for patients with symptoms suggestive of MG but who do not have AChR antibodies. Double seronegative MG (dSNMG) is a term used for patients with symptoms of MG and no AChR or MuSK antibodies. For patients without the antibodies, diagnosis is based on the clinical symptoms, diagnostic testing including edrophonium testing and/or electrophysiological findings. SNMG constitutes about 25% of the autoimmune MG patients. Seronegative and seropositive MG patients manifest similar clinical features, except that seronegative patients tend to have milder disease. It is also important to repeat antibody testing in SNMG patients within 6 months of their disease onset, as seroconversion (presence of antibodies) is not rare within the first 6 months of disease onset. Edrophonium chloride is a short-acting, reversible acetylcholinesterase inhibitor. It inhibits the breakdown of acetylcholine, which is a neurotransmitter that is released at the neuromuscular junction. The physician has to make sure that there is an objective parameter to measure before and after the test is performed, e.g. ptosis (droopy eyelid). Edrophonium testing (commonly referred to as Tensilon or Enlon testing) is performed by injecting edrophonium chloride and observing the response, e.g. improvement in ptosis. The positive response is seen within 5-15 minutes and is brief. Repetitive nerve stimulation (RNS) is one of the electrodiagnostic tests used for the diagnosis. The facial, ulnar or accessory nerve is stimulated at 3Hz and compound muscle action potential (CMAP) is recorded over the muscle. Significant decrement is found in about 60% of patients with MG. Sensitivity is about 76%. Single Fiber Electromyogram (SFEMG) is done with patient making minor sustained contraction of the muscle and recording with either single fiber needle or concentric needle. Stimulation with a small amount of current while recording is used in some situations. The muscle for testing is selected based on the symptoms of the patient. Usually the weakest muscle on examination is selected for testing. The measurement of jitter by SFEMG is the most sensitive clinical test of neuromuscular transmission. It is abnormal in more than 90% of MG patients. However, this can be abnormal in other conditions like myopathies and motor neuron disease. Although the various tests help us with diagnosis of MG in the majority of the patients, the sensitivity is not 100% with any test, therefore clinical evaluation by physician is an important aspect of the diagnosis and making sure there is no other cause for the symptoms, as a few other conditions can look like MG, especially in ocular MG. The most important feature that distinguishes MG from other conditions is the fluctuations and fatigability of the symptoms and signs. It is also important to evaluate for possible congenital myasthenic syndrome in some of the SNMG patients, especially young patients with symptoms suggestive of MG and negative diagnostic or antibody tests.
A MESSAGE FROM THE MGA’S EXECUTIVE DIRECTOR

These last three months have been an exciting and transitional time for the MGA as I started my new role and began getting my feet wet. One of the biggest dreams I have for the MGA is that people will recognize us just as they recognize the pink for breast cancer or purple ribbons for Alzheimer’s. Making that dream come true means working hard to make footprints in each of the communities we are apart of and engaging with each of you to see how we can pull that off. I have thoroughly enjoyed getting to meet many of your faces as I have shadowed at our KC clinics and support groups across the Heartland. If I haven’t met you yet, I will! Behind the scenes we have been developing plans for an Under 50 Social Group, website redesign through a grant received with CompileKC, revitalization of the Columbia, MO Support Group, and an upgraded donor database. It’s a breath of fresh air to go to work each day and have the ability to network and connect with others who have spent much of their lives battling the same disease I have. Here’s to our future and the work to be done in the Heartland! Allison Foss, Executive Director

The 8th Annual MGA Triple Crown Showdown is nearly a month away on May 20, 2018! Are you registered? Individuals with MG can register for FREE using the code MGA2018. Family & Friends can register for 20% off using code MGAFAMILY18. In order to be ensured a t-shirt you must register in advance at www.mga5k.com. Volunteers are still needed to help us monitor the course. Signing up is easy when you go to www.mga5k.com and click Volunteer. We hope you’ll join us for this family friendly event!
News from Washington on Rare Disease Research and Patients’ Needs
- In the bipartisan budget agreement of February 2018, the NIH saw a funding boost of $2 billion to support additional scientific research, raising the NIH’s total budget to $36.1 billion. Much of this increase will be used in the fight against rare diseases - to hire experts, conduct clinical trials and shepherd research.
- In 2017, the Benefit Act was introduced into Congress. It stands for “Better Empowerment Now to Enhance Framework and Improve Treatments” and is an effort to have the FDA include patient experience as part of its risk-benefit framework. The legislation, which strengthens patient participation and the “patient experience” in drug development, has been endorsed by a wide range of advocacy groups. Passed by the Senate in 2017, the Benefit Act now awaits a House vote.
- The Orphan Drug Tax Credit, an incentive for pharmaceutical companies to seek treatments and cures for rare diseases, provides them a tax credit of 50% of qualified clinical drug testing expenses. Congress slashed it nearly in half late last year. The House voted 227-205 to repeal it entirely, but the Senate ended up lowering the percentage of qualified expenses from 50% to 27.5%. NORD, the National Organization for Rare Diseases, which lobbied hard to preserve it, claims that the credit — which also gives drug companies seven years of exclusivity to market approved therapies — has led to the approval of 451 orphan drugs for 590 rare disease indications since its passage in 1983.
- In what’s dubbed the “Right to Try” controversy, the House on March 21, 2018, passed what is termed a ‘Right to Try’ bill, which gives terminally ill patients the right to seek drug treatments that remain in clinical trials and have passed phase one of the FDA’s approval process, but have not been fully approved by the FDA. The legislation now goes to the Senate. Right-to-try laws exist in 38 states, including Missouri and Arkansas, but this would introduce legislation across state lines. (To read the news release, go to: https://www.cnn.com/2018/03/22/health/federal-right-to-try-explainer/index.html). NORD, the FDA and 37 patient advocacy groups have publicly expressed opposition to the Right to Try. In NORD’s opinion the law under consideration, among other things, “may possibly harm patients by exposing them to bad actors looking to profit off of false hope”.

To read the full news report on all of the above issues, go to: https://myastheniagravisnews.com/2018/03/08/us-lawmakers-urge-bipartisan-support-rare-disease-research-patients-needs/

Young MGer’s Social Group forms
The inaugural meeting of the young MGer’s social group was held on Tuesday April 10th at Cacao in Prairie Village. It was a great evening of sharing stories, battle wounds and laughter! The next gathering is set for July 10th at 6pm Cinzetti’s in Overland Park. We hope to see you there!

In Memoriam
Virginia Cassidy
St. Louis, MO
Chuck Toy
Valley Falls, KS
Earl Castleberry
Grantsville, KS
Noreen Herzog
St. Louis, MO
Krishawna Grant
Kansas City, MO
Walter Farnsworth
Olathe, KS
Arnold Hancock
Bulter, MO
Ron Boeve
Phillipsburg, KS

DISCLAIMER: Please note that any medical or personal views expressed in this newsletter are those of the individual author(s) and do not reflect any official position of the Myasthenia Gravis Association. The information presented in this newsletter is not intended as medical advice. Each patient’s situation is unique, and treatment, diagnosis and other decisions should be determined in consultation with the patient’s doctor(s). If you have any medical questions, please discuss them with your doctor, as he or she best knows your situation.
You’ve got our heart.
We’ve got your back.

We ❤️ making our patients 😊
Learn how ARJ’s life-changing IVlg treatments help people across Kansas City.

arjInfusion.com/Journey
866-451-8804

ARJ’s advanced IVlg program provides immune globulin infusion therapy to children and adults with myasthenia gravis.

With nationwide pharmacy coverage and 24/7 clinical support, we’re on a mission to transform our patients’ lives—one unique journey at a time.
Clinical Trials

Kansas University Medical Center in Kansas City, KS, is participating in several clinical trials relating to myasthenia gravis (see below). If you are interested in participating in a trial or would like more information, go to clinicaltrials.gov, and enter the NCT number related to the specific trial. You can also call KU directly and talk to Laura Herbelin 913-588-5095.

1. A Phase 2, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Safety, Tolerability, and Preliminary Efficacy of RA101495 in Subjects with Generalized Myasthenia Gravis NCT03315130
2. Efficacy and Safety of IGIV-C in Corticosteroid Dependent Patients With Generalized Myasthenia Gravis -NCT02473965
4. Study to Test the Safety, Tolerability, and Efficacy of UCB7665 in Subjects with Moderate to Severe MG - NCT03052751
5. Efficacy and safety of amifampridine phosphate in improving the activities of daily living for patients with antibody positive MuSK myasthenia gravis. NCT03304054

2018 MGA Board Members & Staff

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Program Coordinator: Anne Strader

MYASTHENICS AND MUSCLE CRAMPS

Muscle cramps seem to be a common problem among MG patients. Muscles require calcium, potassium and sodium to work properly. For relief of muscle cramps you might try the follow solutions, but check with your doctor first.

**Calcium** - Dictum dicalcium phosphate tablets crushed between your teeth before swallowing usually work in 10 to 15 minutes. Calcium carbonate, aka Tums, also helps prevent cramps. It is absorbed much more slowly than dicalcium phosphate and is more useful as a preventative. It is also a very good antacid and does not contain magnesium which many antacids contain.

**Potassium** – It is important to have adequate potassium to prevent muscle problems. Too much can also cause muscles cramps. That is why most potassium tablets, capsules and liquids require a prescription. Potassium can also irritate the stomach. It is much better to get this mineral from potassium rich foods such as white beans, dark leafy greens, potatoes, dried apricots, acorn squash, yogurt (plain skim non-fat), fish, avocados, mushrooms and bananas.

**Salt** – An adequate amount of salt (sodium chloride) is needed to prevent muscle cramps as well. An MG patient shouldn’t go on a low-salt diet unless specifically recommended by his or her doctor. Most canned and prepared foods already have a high sodium content, so it is better to use the salt shaker sparingly. MG patients who are certain they do not have high blood pressure (or other prohibitive conditions) can usually relieve muscle cramps by eating a salty snack, such as pretzels. Prednisone can cause fluid retention caused by sodium retention so a salt-restricted diet may be ordered for those taking it.

It is particularly important for MG patients to have the proper amount of calcium, potassium and sodium in their blood. Anytime you have a blood test done, ask your doctor for a copy of the lab report. It will show the amount of calcium, potassium and sodium. It also shows the normal range for each.

Do not use over-the-counter preparations for muscle cramps, as these may contain quinine which can cause myasthenic muscles to stop working. Overuse of weak muscles will cause muscle cramps. Levels of activity you can tolerate reasonably will help keep your muscles in good condition. Vitamin deficiency, hypothyroidism, dehydration and low magnesium are also possible causes of muscle cramps and should be considered if you have MG. Again, always check with your doctor before taking any supplements.

Excerpted from MG Association of British Columbia article: https://myastheniagravis.ca/article-myasthenics-and-muscle-cramps/
Katelyn Steele Joins the Medical Advisory Committee
Katelyn Steele, PharmD, CGP has joined the Medical Advisory Committee. Steele is a 2014 graduate of the University of Kansas and is a board certified geriatric pharmacist. Katelyn is employed at Balls Food Stores and specializes in medication therapy management and is an adjunct clinical professor with the University of Kansas. Katelyn and her husband, Brian, live in Prairie Village with son, Graham.

Hubers & Beck Join the Board of Directors
Stephanie Hubers & Brodie Beck have joined the Board of Directors. Hubers has volunteered with the MGA through the MGA Triple Crown Showdown Committee since 2014. Stephanie is a graduate of Dordt College where she received a degree in Business Administration and she currently works as a Program Manager at Iris Marketing in Lenexa. She lives with her husband, Jeremy, in Overland Park. Beck, who has volunteered for the MGA through the Triple Crown Showdown and at Cy’s Crown Town Trivia is a Clinical Researcher at Novartis. He has worked in the clinical science industry for the last eight years following his graduation from the University of Kansas with a B.S. in Business Finance and Molecular Biology. He lives in Overland Park with his dog, Ollie. The Board of Directors is excited to have Stephanie and Brodie on Board!

KU Medical Student Interviews Larry Paxson
Larry Paxson of Wichita was recently showcased by Russell Locks who is an MD student with KUMC in Wichita for a medical school project. Paxson, who has been living with MG, and his wife Dana lead the Wichita Support Group. Locks interviewed Larry to gather more information about myasthenia gravis, his treatment and what would be beneficial for medical professionals in training to understand about myasthenia gravis. The more you know!

2017 by the numbers
31 Support Group meetings in 6 different cities with 554 attending
74 New patient packets mailed out
69 Clinics held with 360 individuals seen
7 Hospital visits
490 Participants for the 7th Annual MGA Triple Crown Showdown where $40,000 was raised.
100 Participants, families & volunteers for the Wichita Walk for Awareness
140 Participants helped raise $18,500 at the 1st Annual Cy’s Crown Town Trivia
89 in attendance for the Annual Meeting
1471 MGA Connections newsletters mailed every quarter to patients, families & medical professionals
6500 Likes on Facebook
800 Followers on Twitter
Thanks for being part of a great year! We look forward to working with you in 2018!
<table>
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<tr>
<th>Area</th>
<th>Dates</th>
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<th>Location</th>
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</thead>
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| Kansas City, MO | April 28th  
August 4th | 11am-1:00pm | St. Joseph Medical Center ~ Community Center  
1000 Carondelet Drive, KCMO 64114  
RSVP mgakc@sbcglobal.net or (816) 256-4100 |
|              | July 28th  
Oct. 6th       |            |                                                                           |
|              | July 28th  
Oct. 6th       |            |                                                                           |
| KC Northland | May 10th  
July 12th  
Sept. 13th | noon-1:30pm | Primrose Retirement Communities  
8559 N Line Creek Pkwy, KCMO 64151  
RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| Columbia, MO | July 17th | 6:30-8pm | Location TBD                                                              |
| Springfield, MO | May 17th   | 6-8pm | The Library Center  
4653 S. Campbell  
Springfield, MO 65810  
RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| St. Louis    | June 9th | 10am-11:30am | Location TBD                                                              |
| Wichita, KS  | April 28th  
May 12th  
June 9th  
July 21st  
August 4th | 1-3pm | Via Christi Medical Center  
Saint Francis Campus 929 N St Francis St  
Wichita, KS 67214  
Contact: Dana or Larry Paxson for more info or to RSVP  
dkptiffany@gmail.com or (316) 269-9120 |
| Manhattan, KS | TBD       | TBD | Manhattan Public Library—Friends Room  
629 Poyntz Ave, Manhattan, KS 66502  
RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| Omaha, NE    | April 14th  
May 12th  
June 9th  
July 14th  
August 11th | 10am-noon | Calvary Lutheran Church  
2941 N 80th St, Omaha, NE 68134  
Contact: Dianna McCarty for info or to RSVP  
dmccarty@abbnebraska.com or (402)426-8006  
Kathy Cassidy - cassidykathryn@yahoo.com or  
402-719-5861 |
| Northwest, AR | April 29th  
July 8th | 2:30-4:30pm | Schmieding Center for Senior Health and Education  
2422 N. Thompson (Hwy 71 North)  
Springdale  
Contact: Roger Huff for more info or to RSVP  
jrhuff1@cox.net or (479) 790-3022 |
|              | Annual Conference—Oct. 6th |            |                                                                           |

* Please check with coordinator to insure date & location have not changed
Drs. Mazen M. Dimachkie and Richard J. Barohn of the Kansas University Medical Center are delighted to share with the MGA community that a book about MG and related disorders is about to be published. This is after the publisher of Neurologic Clinics of North America asked Drs. Dimachkie and Barohn to be co-editors of this publication dedicated to neuromuscular junction defects.

The table of contents of this issue is comprehensive. Below are the topics of this publication which gives MGA community members a taste of what is to come. Part of their plan is to educate people with MG and their friends and family. Drs. Dimachkie and Barohn will be providing in upcoming MGA newsletters a summary of the relevant topics discussed in the publication which is due to be released May 1, 2018.

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MAZEN M. DIMACHKIE, MD, FAAN, FANA
Director, Neuromuscular Division, Executive Vice Chairman, Vice Chairman for Research Programs, Professor, Department of Neurology, Associate Director, Institute for Neurological Discoveries, University of Kansas Medical Center, Kansas City, Kansas, USA

RICHARD J. BAROHN, MD
Gertrude and Dewey Ziegler Professor of Neurology, University Distinguished Professor, Chairman, Vice Chancellor of Research, President, Research Institute, Director, FRONTIERS, The Heartland Institute for Clinical and Translational Research, University of Kansas Clinical and Translational Science Institute, University of Kansas Medical Center, Kansas City, Kansas, USA

A very special thanks to Leinenkugel’s KC for hosting the MGA for their 1st quarter FILLanthropy. $244 was raised through the campaign! Thank you to Jeremy and Stephanie Hubers and Kyle Flander for representing the MGA and picking up the check. Thanks for your support!
**Effectiveness of selective plasma exchange therapy in patients with MG** Selective plasma exchange (SePE) is a new modality of plasmapheresis (PE) using a membrane plasma separator with smaller than ordinary pores. SePE can remove IgG and cytokines while retaining high molecular weight substances such as fibrinogen and factor 13 which are coagulation factor components. The aim of the study was to investigate the effectiveness and safety of SePE in treating MG patients. Japanese researchers retrospectively reviewed the medical records of 18 MG patients treated for exacerbated conditions for the year 2016. There were 10 patients who had PE with albumin replacement. Among them, 5 patients were treated with conventional PE and the other 5 patients with SePE. The median age and mean disease duration were almost the same for the two groups. The median QMG scores before treatment were 17 in the PE group and 13 in the SePE group. The median QMG scores after treatment were 9 in the PE group and 7 in the SePE group. There were no systemic complications such as hypotension or dyspnea in either group. The researchers concluded that SePE had a comparable therapeutic effect to and would be safer than conventional PE.

**Quality of life among MG patients is worse in women than men, but removing the thymus in women eliminates this disparity** University of Alabama researchers investigated the quality of life of 1,315 adults, including 827 women, with MG using a U.S. database called the MG Patient Registry. Patients’ demographic information and disease-related history were analyzed, and disability, fatigue, depression, and quality of life were assessed through self-reported measurement systems. Female participants were significantly younger, had disease symptoms at a younger age, and took longer to be diagnosed, compared with men. They were also more likely to have thymus abnormalities and to have undergone thymus removal. Participants in general reported a poor quality of life, but the effects were worse in women. This gender disparity in quality of life disappeared when comparing men and women who had their thymus removed. Thymus removal improved quality of life in women, but not in men, suggesting that men do not respond to thymus removal as well as women. “Our study demonstrates gender differences in MG and provides valuable clues that the thymus might play an important role as a mediator,” the team wrote. Read the full article at: https://myastheniagravisnews.com/2018/03/15/thymus-removal-improves-quality-of-life-women-myasthenia-gravis-study/

**The chemistry behind stress hijacking your immune system** Researchers at the University of Michigan have identified how stress interacts with cells that are supposed to protect the body against infectious diseases and manifest into physical illness. Their study revealed that stress can affect the response of 'defense chemicals', or substances that fight bacteria or viruses, strengthen inflammatory and allergic reactions such as irritable bowel syndrome, asthma and autoimmune disorders such as lupus. Doctors can start prescribing stress management tools like breathing exercises and yoga to treat disorders like asthma and irritable bowel syndrome symptoms. Stress receptors, known as corticotropin release factors (CRF1), send signals to certain immune cells, called mast cells, and control how they maintain the body. Mast cells, a type of white blood cell, are involved with inflammatory responses such as hypersensitivity and allergic reactions when the immune system responds to perceived threats. When mast cells are triggered during stressful situations, they are vulnerable to control by stress receptors. "If this happens, CRF1 tells these cells to release chemicals that can cause inflammatory and allergic diseases such as irritable bowel syndrome, asthma, life-threatening food allergies and autoimmune disorders such as lupus. To read the full story, go to: http://www.en.netralnews.com/news/health/read/17641/stress.can.cause.physical.illness..here.is.why
Are you an MGer and a business owner? We have started a new database and want to know your info! We would love to be able to help promote, share and utilize businesses owned by MGers! Contact Allison Foss at allisonfoss@mgakc.org to share your business info. Thanks!

Let’s go PAPERLESS! Wanna chance to win an AMC gift card? Sign up to receive the newsletter via EMAIL ONLY and you will be entered! Email allisonfoss@mgakc.org

We are excited to share with you that the 2nd Annual CY’S Crown Town Trivia Night benefitting the MGA will take place on Friday, September 28th at Boulevard Brewing Company in Kansas City! It will be an exciting night of trivia, silent auctions, live auctions, food, brews and wine. We hope you’ll join us. Tickets available soon!

Did you know you can shop at Lauren’s Hope and it benefits the MGA? Lauren’s Hope has fashionable medical IDs. Be sure to use this link to make your purchases! Thanks for your support!
http://shrsrl.com/sjde
Memorial Contributions

Earl Hartter  
Lenexa, KS  
Douglas Garber  
Sue Brockhoff  
Ronald and Karen Fenton  
Kenmark INC  
Patrick and Judy Collins  
Thomas and Cleo Murphy  
Lux Trust  
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Linda Voelker

Jack Gray  
Springfield, MO  
Robert and Judy Gray

Cheryl Paul  
Lenexa, KS  
Gary Paul  
Don & Katie Morris  
Charlotte Blitsch

Pictures from around the MGA of the Heartland

St. Louis Support Group meeting in March led by Hayward Liebling at Glendale Presbyterian Church.

Members of the Wichita support group participated in the Wichita State University Health Resource Fair on February 28th. They handed out MG literature and spoke to over 175 attendees about myasthenia gravis. Thank you Dana and Larry Paxson for arranging this opportunity for the MGA. Also a huge thank you to Jill Rust, Ellen and Bill Goodwin, Shawna and Dan Taylor and Beverly Elder for assisting at the booth.
MGA Receives Grant for Website Redesign through Compile KC

The MGA recently received a grant through Compile KC in which individuals from local technology companies provided services for web redesign over the weekend of April 13th. Three individuals were assigned to the MGA and spent 48 hours redesigning the website to make it more user friendly, interactive and to give it a fresh look. A huge thanks goes out to our Cody and John with Compile KC as well as Harold Davidson, Mia Hawkins and Anna Scheuler, who were behind the keys and screen to make the website redesign possible. Because of this grant, the MGA was able to cancel an ongoing monthly contract with an IT company for web support and services. If you haven’t checked it out yet be sure to head on over to www.mgakc.org. Let us know what you think!

MGA CONNECTIONS

Are you newly diagnosed and looking for support and answers? Have you lived with MG for years and want to share your experiences? For anyone looking to talk to others who have MG, we have MGA Connections! Give us a call and we will send you the full list or help make suggestions of people you may benefit connecting with by email or phone.
MY SERONEGATIVE ODYSSEY

I am Jane Doe. I am 52 years old. I have been asked to share the story of my experience of having Seronegative Myasthenia Gravis. I also have negative Repetitive Nerve Stimulation and Single Fiber EMG tests. I have a multitude of symptoms: fluctuating ptosis, diplopia, dysarthria, dysphagia, dysphonia, shortness of breath, respiratory muscle weakness, fatigable limb weakness, neck flexor weakness, difficulty chewing, smiling, sitting upright or standing for more than a few minutes. These symptoms caused, and still cause, a complete breakdown in life as I knew it. Yet, after visiting 5 Neurologists and 2 Neuro-Ophthalmologists from the top 3 University systems in my state, I was unable to secure a diagnosis and was told it was from my mental health and “that if my brain wanted my body to do this, it would”. Mis-diagnoses included Sjogren’s Syndrome, fibromyalgia, possible cerebral aneurysm, anxiety attacks, cataracts, among others. I’ve endured much testing, some several times – all negative. I was sent to a psychologist who determined there was nothing psychologically causing my symptoms. After begging for Mestinon, the first dose was like a miracle, but after a few months, my symptoms were increasing again. Still no diagnosis. I was told the SFEMG was the gold standard for diagnosis, so I was repeatedly dismissed for MG. It was devastating and dehumanizing.

I had nowhere else to turn. As a registered nurse of nearly 30 years, I knew I had to get help. In May 2017, I traveled out of state to consult with a neurologist who is on the MGFA Medical Board. I was afraid I would die without treatment, due to my breathing difficulties. I had already lost my job, one that I held for 20 years. He was my last hope. If he said it was all in my head, I would quit my pursuit and possibly search for a mental hospital. He said my EMG results were borderline, not negative. He noted my response to Mestinon, IVIG and prednisone. I will never forget his words to me. After a careful review of all my previous testing, a detailed clinical exam, and many questions, he said nothing else could explain my presentation. I was diagnosed with generalized seronegative myasthenia gravis. He was then able to work with my local neurologist to start my treatment of increased Mestinon, Prednisone, and Cellcept. I am on my 9th month of treatment and noticing overall improvements, despite a setback from a failed attempt to wean Prednisone. I also now use a portable ventilator at night, and as needed, for the weakness of my breathing muscles. I have had moments that I have felt good. I am so grateful for a diagnosis and treatment, although I am still terrified that if I must be hospitalized locally, my diagnosis will be questioned, and my care may be compromised.

Now I am in a position to try to help others. As a member of the seronegative community and the Facebook seronegative group of over 1200 active members worldwide, I have seen this happen repeatedly. Our members are often undiagnosed and/or left untreated, even when they present to the emergency room with clear signs of respiratory compromise. I encourage them to learn all they can about MG, reach out to others, including the MGA and the MGFA, and never give up trying to find a physician that they can develop a relationship with. Being a rare presentation of a rare disease is not easy, for us or for our physicians. Even though it may take time and more than one physician, find one who will work with you to help you find the answers you deserve. I am forever grateful to the MGA for their care and concern during my journey.

Please join us in Wichita on October 6, 2018 at OJ Watson Park for the MGA Snowflake Shuffle 0.1K. More details to come!
2018 membership/fundraising drive

Please keep the MGA on your list as you make charitable donations. The MGA’s annual membership drive benefits those with MG and their families and caregivers through our referrals, newsletters, support groups, clinics, new patient packets, and one-on-one consultations.

Thank you to those who have become members since our last newsletter!

Steven Brinker
Doris Glover
Lynne & Ruth Smith
Lorraine Boyd
Janice Frazer
Cheryl Swann
Bobbie Jane Gates
Virgil Wittl
Ann Mowry
Harold Thaut, MD
Derek Haverkamp
Helen Stefanov in memory of
Jan Stefanov
John Sand, MD
Donald Sisson

Dennis & Liz Wise
Gail McPeak
Floyd & Marjorie Gentry
Richard & Janice McGuire
R & S Fitzthum
Daniel & Denise Cogan
Arthur & LaQuita King
Daniel & Donna Gifford
Jimmy & Marilyn Williams
Gary Ward in memory of Terry Ward
and in honor of Lisa, Amy & Julie
Pam Blend
Lynda Hirsekorn in memory of
Sheldon Hollub
Diana Wilmoth

Norma & Ann Covington
Ronald Walker
Jack & Beverly Gant
Frances Montgomery in memory
of Joseph Montgomery
Charles & Mary Haley
Anita & Everett Jenkins
Brenda Spencer
Greg Shamburg
William & Joan Stackhouse
Dorothy Jackson Canady
Richard Perry
Allison Foss
Brett Henson

The MGA can now accept donations via Venmo! Donate via your Venmo app

Please become a 2018 member & receive a tax deduction!

PLEASE PRINT
Cut & enclose in envelope & mail to: ➔

MGA
2340 E. Meyer Blvd.
Bldg.1, Suite 300A
KCMO 64132

PLEASE CHECK:
☐ MG Patient
☐ Relative
☐ Friend

Make checks payable to the Myasthenia Gravis Association: ALL CONTRIBUTIONS ARE TAX-DEDUCTIBLE

☐ $ 25 Basic Membership
☐ $ 58 (58th Anniversary Membership)
☐ $ 100 Sustaining Membership
☐ $ 500 Patron Membership
☐ $ 1,000 Lifetime Membership
☐ $ ______ In Memory of:
☐ $ ______ In Honor of:

Thank You!

If you’d rather pay with a credit card, https://www.firstgiving.com/event/mgakc/2018-membership-drive
The Mission of the MGA

The Myasthenia Gravis Association (MGA) is dedicated to improving the quality of life for those who are affected by this autoimmune, neuromuscular disease, through awareness, education and patient services.

Call us at: (816) 256-4100

~ or ~

Kansas City, MO 64132
Building 1, Suite 300A
2340 E. Meyer Blvd.

Myasthenia Gravis Association
Please send a note to:
address change.

or if you have or will have an
or added to our mailing list.

If you would like to be

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